

Invisible, But Still Real

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In this paper I talk about my personal experience of a number of invisible disabilities including brain injury, infertility, asthma, ulcerative colitis, severe depression and a few invisible orthopaedic injuries. I acknowledge that this discussion is self-orientated, but anyone who has experienced a serious accident like me, whose life has been violently thrown into complete disarray, has an intensely personal story. I think it is really important for disabled people to feel free to discuss their subjective experiences. And I need to be reflective about such a life-changing event to help me come to terms with it. I am certain that many people with invisible disabilities will be able to relate to my story.

I was run over in 1992. In the accident I broke my jaw, cheekbone, radius and ulna, suffered a closed head injury (an acquired brain injury), punctured my lung and ruptured my knee. My stomach was also cut in half and was stapled back together. I was also made infertile. My asthma, which had been manageable, suddenly became much worse as a result of the punctured lung. These injuries meant that I was in a dangerously ill condition in Intensive Care. My parents were told that I might not live and that I certainly would not work again. Doctors suggested that my family kiss me goodbye before they left the hospital.

Despite these early pessimistic predictions, I did survive the accident. I emerged from it a different person with a number of invisible disabilities. One invisible disability is my asthma. It has been much worse because of my punctured lung. Another invisible disability is the pain in my knee. After I was hit by the first car, I was thrown into the path of a second car which ran over my knee. I had an arthroscopy on my knee which did not leave any visible scars. And yet the area still causes me a lot of pain and discomfort. A third invisible disability is the problem I have with my right arm. My radius and ulna were so badly broken that some of the bone had to be cut out and the remaining bones fused together. The scar is tiny, almost imperceptible, but the injury has sapped the strength in my arm and caused a great deal of pain. A fourth invisible disability is that I am now infertile. This has greatly affected my self-image. Another disability is that I now experience severe depression and mood swings. And a sixth invisible disability is my brain injury, which has caused a complete change in personality, thought patterns and behaviour.

Even though you can not see my brain injury, you can see some of its effects. For instance, I am much clumsier. Almost every day, I spill my food or drinks over my clothes. I am always having little accidents and my sense of space has completely changed too. Another effect of my brain injury is that fatigue and weariness are my constant companions. People often assume that I am lazy or that I am unmotivated because I complain of fatigue. But that is not true at all. Often, I do fight my fatigue, but when I do I sometimes end up being exhausted for another week or getting hurt because my senses are not functioning at full capacity. I often have falls when I am tired. Last year I broke my wrist and my ribs in two separate falls.

My memory, which is bad at the best of times, also gets worse when I am tired. Memory problems are one of the worst features of my brain injury. I always go to the shops meaning to buy one thing and buying another, I get lost even in the most familiar places, and I can not even remember my wife's phone number at work. I forget the names of good friends and I live in dread that one day I will not be able to remember my wife's name. Such fears do have some foundation: I often can not remember the names of people who are very important to me and I get lost in "familiar" places. One time I was working on the computer and I decided to make a cup of tea. When I reached the kitchen I could not remember where my desk was. I stood there, lost, and ended up crying like a blubbering idiot.

Another result of my brain injury is that I can sometimes have problems with words. Sometimes the words I say are not the ones I mean. For instance, I can remember having a dizzy spell at home and falling over. I was alone, except my dog Wally was in the house. I was very cold and I thought that if the dog laid next to me, he might warm me up. I could barely move because of my dizziness. I kept calling out "Mum", but the dog did not come. I did not realise that the dog's name was not Mum for about an hour. A similar example of word-finding difficulties was when I asked my nephew to come and help us eat the "ham we got for chicken" instead of the "ham we got for Christmas".

Before I had the accident I had a sense of certainty because I had a reliable memory. Now, I just have uncertainty. I am never sure if I have forgotten something or if I have remembered it correctly. It is like I have mental cloudiness. Often the things I do remember are incomplete or in some ways inaccurate. And my ability to concentrate even for a short time has diminished. Adjusting to all these changes has been quite an emotional challenge in itself. I have probably had to work harder on my emotional recovery than on my physical one. It has taken me a long time to learn how to cope with the changes to my body and to myself. There were moments when I was gripped with absolute despair. In those times I saw a blackness in my spirit that I never knew existed. Nothing was the same, my energy was gone, my spirit was shattered, my body was violated, my sense of fun had gone.

So even though I have few visible scars, I carry my disabilities with me everywhere. I am haunted by memories of my accident. I continually remember lying on the ground after the van hit me, writhing in agony. I remember the blood filling my mouth to the point when I thought it would choke me. I also remember a well-intentioned bystander running over and rolling me onto my side, straight onto my punctured lung. I tried to scream but I could not, as I had no breath. I tried to tell him to stop, but no sound came out of my mouth. I tried to move but I could not. I felt my lung collapsing under his pressure. Blood poured out of my mouth like a tap being turned on full. I can remember being really cold, freezing. And I passed out.

As a result of this experience, I suffered anoxia (lack of oxygen to the brain). I was very near death, but I sensed that I would live. Somehow, I am not sure how, I knew that this was not my time. I knew I was not going to die.

Once I entered the hospital system I began to be supplied with drugs, drips, oxygen, antibiotics, pethidine, operations and alike - things which at first which were too much to take in, but which in retrospect saved my life. I only vaguely remember Intensive Care and my memories are mixed with hallucinations. One that stands out was when I felt I went to heaven and some beings told me it was my time to die. They said to relax and accept it, but I refused to go along with their plans. I kept saying, "I can't die." I was so adamant that it was not my time to die that I was sent back here. I was so full of pethidine that I will never be sure as to what really happened and what I imagined. Many of my memories of hospital are like shattered pieces of the past that I am always trying to put together. Overall, my memories are like a jigsaw with a few pieces missing.

I vaguely remember waking up and being transferred out of intensive care after I vomited on an orderly and a nurse. I can remember them changing me from one bed to another, vomiting again on those new sheets and being transferred to another ward. I can also remember someone (and I think this was in ICU) taking a tube out of my lungs through my throat. I can remember gagging on it as they pulled it out and not being able to breathe. I still gag sometimes when I think about that. I am not sure if my vocal chords were bruised. I think they might have been. I can vaguely remember only being able to speak in whispers.

When I was in hospital the doctors would never share any information with me. I resented their power over me, and their refusal to share information, enormously. The power imbalance was symbolised in the charts that they wrote in. Sometimes, as I got better, I would take the charts to the toilet with me so I could see what the doctors were writing. This

was my one act of defiance, my way of saying that I ought to be fully informed about what is being written about me. I would always get in trouble if they found me reading the charts as if I had no right to information about my health.

There are so many paradoxes about my recovery. I had to put the accident behind me, but I had to weave the experience somehow into my own future. I had to take an active role in my recovery, but also had to accept help. I had to challenge medical authority at times, but also be a compliant patient. And I had to tell some people everything about my accident and hide it from others. These were all new challenges for me.

Another memorable hospital experience was the first time I was allowed to shower after my accident. I remember a nurse sponging me and towelling me and when she came to sponge my groin she screamed. Until that stage I didn't know there was anything wrong. I looked down and saw that my sexual organs were completely black with bruising. All the blood inside was quite a frightening sight. The nurse said, "That looks awful." I subsequently found out that I had been made infertile. Being infertile altered my whole identity and sexuality. Another invisible disability, another emotional roller coaster.

It is definitely the little things that I notice the most. For instance, a few months before my accident I had bought some nice outfits for work. I had a blue shirt and a pair of grey trousers that quickly became my favourites because they were so comfortable. I was wearing both of these when I was run over. Someone, I presume in casualty, cut my shirt and my trousers off me. Then they gave them back to me in the hospital, in tatters. Eight years later, I still have those trousers and I still have that shirt, cut into shreds. I have left them at my Mum's house. I can not bring them back home with me because of the emotional pain involved, but I can not get rid of them either. They were after all my favourites, or at least the favourites of the old me. The clothes, like a part of me, are left in limbo.

As I recovered, I felt dizzy whenever I tried to walk. I told the doctors, the physio and the nurses in the hospital, and they said it would go away within a couple of weeks. Then when the dizzy spells were still with me after a couple of weeks, they said that maybe it might take a couple of months. Eventually I went to see a neurosurgeon who said, "You have brain damage. You'll never get over it. You can't recover from brain damage." Everything he said had the same pessimistic tone. Basically, he encouraged me to write the rest of my life off because of my brain injury.

Doctors have incredible amounts of power when you first enter the alien world of brain injury. They have authority and the power to diagnose. The power to label. The power to influence people's lives, expectations and futures. I only wish they would sometimes use that power more thoughtfully. For instance, I wish that neurosurgeon had told me that I could adjust to the challenges of a brain injury. I wish he had put me in touch with other survivors so I did not feel so alone and isolated.

The doctors did not believe that I could have a full and rich life after brain injury so I developed my dreams myself. After I got out of hospital, I wrote myself a note that outlined my aim of recovery and survival:

I believe that the hardest thing about acquired brain injuries is bouncing back, that is, to accept that you have become a new person, to address the problems that you encounter as a result of your injuries, and to move on to learn new skills and take your life in new directions. To bounce back from a head injury takes a lot of effort, as well as determination, support, courage and strength. But it offers the priceless reward of living each day more fully, with wiser perspectives, better humour and more enjoyment.

After I had the dizzy spells for about three years, I decided to apply for a disabled parking permit. I realised that I needed to reduce the amount of walking I did in order to

minimise my dizzy spells. When I got the permit and I started parking in disabled parking spots, I would regularly be abused by people who assumed I was not disabled. One time someone left a note on the car stating "The next time I see you parking here I will scratch HANDICAPPED into your bonnet". This experience profoundly affected me. I grieved because my disabilities were invisible. At the time, I wished that I was a wheelchair user. I thought that if I were in a wheelchair, people would not question whether I was a bona fide disabled person.

Since then, many more people have questioned why I park in disabled parking spaces. They act as if they are the 'Disability Police' and I have to demonstrate my bona fides to them. People regularly ask "How are you disabled?" I have come to expect such questions as a part of life. Because this sort of intrusive question happens regularly, I have become more assertive. I know that I have a legitimate right to use those parking spaces. Now I just say, "Look, I've got a disabled sticker, leave me alone".

In the same way as people question whether I have a disability in a car park, I guess it was inevitable that some health professionals would question my invisible disabilities. This happened when I went to sue the insurance company of one of the people who ran me over. I guess the question of malingering is always present when health professionals see someone with an invisible disability. And one of the results of my brain injury -dizziness - is invisible and very hard to describe. So I underwent repeated neuropsychological testing since my accident. Each one of them has a range of humiliating questions designed to test if I am "really" disabled or just faking it. I sometimes wonder if the professionals who administer these tests assume that I am too stupid to be offended by their questions or whether they simply do not care that they are offending me.

No health care professional has ever been of much assistance to me with regard to my dizziness. So in the eight years since my accident, I have worked out my own ways of dealing with the challenges of dizzy spells. I walk a bit slower. I plan my days so that I do not have to walk far, I do not have to walk fast and I do not have to walk up steps or steep inclines. Avoiding these things seems to make my dizzy spells less intense and less frequent.

The amount of professional intervention in the lives of disabled people never ceases to amaze me. In my own case, I have seen well over three hundred health care professionals in the last eight years. Neuropsychologists, neurosurgeons, physicians, general practitioners, orthopaedic surgeons, rehabilitation counsellors, occupational therapists, physiotherapists, neurophysiotherapists, psychiatrists, psychologists, social workers and many, many more. My accident must have generated a lot of profits for the health system! For many years, my week was not organised from Monday to Friday, but from one appointment with a health professional to another. For instance I might go to physiotherapy on Monday, then back to my GP, to the psychologist the next day and then to the orthopaedic specialist the next, workers compensation the day after and then back for more physiotherapy on the next. In between these regular visits would be occasional trips to the neurologist, neurosurgeon, psychiatrist, hospital, etc. And the visits never seemed to end - I got to know the receptionists at each of the doctors' surgeries on a first name basis!

Since the accident, my stomach has also caused me continuous trouble. I can hardly sleep at night with the pain in my stomach. And I can not eat without pain. The scar from the operation on my stomach stretches from the bottom of my rib cage to the bottom of my navel. The scar has herniated, requiring further operations, but those operations have been postponed three times due to funding cuts in the public health system. In the process of examining what was wrong with my stomach, the doctors discovered that I had ulcerative colitis as well. Another invisible disability!

Before my accident, I used to fall asleep on my back. But I can not sleep that way anymore because my stomach was cut in half in the accident and causes me constant pain when I lie that way. Now, I now sleep on my side only with a pillow under my stomach to

relieve the pain. And yet I do not find lying on my side very relaxing. It is just the least painful option. Things like that often brought me to despair in the early days after my accident.

After I got home from hospital, I would sometimes try to overcompensate for my injuries. For instance I might carry a bag of groceries inside even if that meant that my arm would ache for the rest of the week. Often I wished I was "over" my accident or I would plan things that I could do when I was "over" it. But there would always be some reminder or some disappointment from my damaged body that would bring me back to reality with a thump. Then I would realise that the changes in my lifestyle are permanent.

For a while, I just needed to stabilise my emotional state, to prevent the ups and downs of recovery from overwhelming me. This was quite a task in itself. My whole sense of safety, both physical and psychological, had been violated. Nightmares, flashbacks and people's intrusive questions made it harder to recover. It took a long time before I could go back to the scene of the accident. When I did, I saw the blood stains still on the road and the paint marks where the traffic police had marked the scene of the accident. I was trying to be cold and clinical, but I was overcome with emotion. Seeing the accident site made me feel so vulnerable again, so violated.

Even today I still softly swear at vans when they pass me, not loud enough for the people to hear, but enough to express my continuing pain. I always check to see if it is the driver who ran me over. And I still can not travel in a car or walk in front of one without being gripped by fear.

For the first few years after my accident, the issue of disclosing my disability was a very hard one. People would ask why I was not working or would see the latest plaster from an operation and want to know what had happened to me. I would regularly be overwhelmed by people's intrusiveness. I would often just break down and cry. Once, at a job interview, someone asked me what had happened to me and all I could do was cry. Needless to say, I did not get the job.

In fact, the issue of disclosure and employment is an interesting one. Work has been very difficult for me since my accident. For the first five years, all I tried to do was get back to the workforce. I went for about forty job interviews and did many work rehabilitation programs. In the process I applied for many jobs. I was never successful on any occasion that I disclosed I had a brain injury. Even saying "I had a serious accident, but I'm ok now" would be enough to ensure I was passed over. Prospective employers saw me as too risky when they knew about my disability. If I did not mention my experience, I would at least get another interview. There were no exceptions to this pattern, none. To me, that says a lot about disability discrimination for people with invisible disabilities.

People have asked me what was the worst thing about my accident and I never hesitate to reply. It was not that I was made infertile. It was not that I had my brain injured. It was not that my body became very fragile as a result of all the injuries. It was that some of my best friends never came to visit me in hospital. This left me with an incredible overriding sense of abandonment. I simply could not believe that they had not come and were not coming. It was particularly hard to deal with because I was combating confusion, tiredness, physical exhaustion and pain all at once. I needed people to support me on the road to recovery. To some extent, I still do now. And it was incredibly difficult for me to come to terms with a new self-image, new behaviours, almost a new life, without the support of any friends.

One of my best friends, who I had known since my first year of high school, was a doctor in the hospital where I was treated. And yet in a year and a half, he could not manage one visit to me. He must have seen hundreds of patients in that time, but could not spare one lunch break to visit me. I feel such a profound sense of loss and betrayal over this. I know I would have behaved differently if he had been injured.

One of the most hurtful elements of my invisible disability is that I have lost all my

friends. When my friends realised that the changes were permanent, they abandoned me. I know I am not alone in this respect. I have chatted with hundreds of brain injury survivors all over the world via the Internet. Losing all your friends seems to happen to a majority of brain injury survivors. Nevertheless, for each one of us, it is an intensely painful experience. It makes you more vulnerable, and it makes your recovery so much harder.

My recovery from the accident has been characterised by highs and lows. My moods have swung in similar fashions. Although I have since learnt that it is very common for people with a head injury to experience mood swings, when I first experienced it I was unprepared. I would become overwhelmed with despair or resignation or even anger in ways that were previously alien to me. The emotional turbulence that I went through overwhelmed me. I asked questions like "Why me?" and "What have I done to deserve this?" But I could never come up with any satisfactory answers. The pain I went through was too severe, persistent and overwhelming. Worse still, the accident was not just a horrible memory, it was continually re-experienced because of post traumatic stress, nightmares and flashbacks.

The accident caused me so much damage, so much pain and so much upheaval into my whole life that for the first year (or two or three) I could see no benefits. It was just a horrible experience that was never far from my thoughts. Every time I had a shower and saw the scars on my body my thoughts went back to the accident. Every time I had pain in my arm, my head, or my ribs I thought of the accident. Every time I got dizzy and fell over I wished the accident had never occurred. I had no energy left to deal with family problems, financial matters or even thinking about returning to work. I had no energy or patience for trivia when my focus was on simply surviving physically and healing emotionally. This made me feel like much of my spirit had been taken away from me.

Prior to the accident I had been very active in many fields. But the combination of dizziness, fatigue, mood swings and pain made such a life style impossible to continue. It was as if the brakes had been slammed down on my hectic life. Tiredness and pain often made me wonder if it was worth going on. It was the incessant nature of my disabilities which made them so difficult to cope with. I could never escape the pain. It was with me all day every day. Winter months were particularly difficult as I got more arthritis in my damaged joints. My restricted mobility and reduced strength made me feel more vulnerable physically and my head injury made me clumsy and slow.

Another one of the hardest changes to deal with after my brain injury was my newly-acquired tendency to be disinhibited. Disinhibition is a classic symptom of having your frontal lobe damaged. Dealing with disinhibition is hard, both for survivors and the people close to us. Your personality changes and you say and do things that you would never have done before. You need support to relearn social skills, but you do not get this support because people usually abandon you once you start behaving differently.

I guess you can look at disinhibition in lots of ways. On the one hand, you could see it as a positive thing. For instance, my disinhibition means that I cannot tell a lie. I simply cannot. I cannot even force myself to. I feel like the character in the movie "Liar Liar." I cannot lie, no matter what. I have to tell the truth and I have to say what I think. Some people see my honesty as a really good quality. On the other hand, being somewhat disinhibited can also cause problems when it results in "socially inappropriate behaviour": saying or doing things that offend others. Again, because the brain injury is invisible, it is often difficult for people to understand the source of the disinhibition.

Of course in my recovery there have been many joys. I have had more happiness than I ever anticipated in the first few years after my accident. The biggest high since my accident was meeting and eventually marrying my wife Jenny. Jenny was the first friend I made after my accident and I met her four years later. Jenny has taught me things that I never saw in myself. She has taught me simple joys like watching television shows that I would have previously dismissed as facile rubbish. Building a happy and healthy relationship with

Jenny has probably been the single best thing for my recovery.

Being in a marriage with a non-disabled person has been interesting too. We have gone to parties where people have asked Jenny "What would Mark like to drink?" (as if I was incapable of answering myself). And when we tried to rent a house, many landlords would balk at the prospect of renting to someone on the disability pension. The fact that Jenny had a stable job working at a bank would be ignored and the emphasis would be put on my status as a disability pensioner. I know from other disabled people that this sort of discrimination is a regular occurrence.

My invisible disabilities have even affected my relationship with Jenny. For instance, we would like to have children. This has meant that we have tried IVF, unsuccessfully, about eight times. I often wish I was not infertile. My infertility has seriously affected our relationship, our moods, our plans and our finances. Infertility is a very costly disability. It costs thousands of dollars to try to have children through IVF. Yet the disability industry has basically ignored people with infertility. Still I know that infertile people are disabled, even if we are ignored in many disability circles.

Another of my experiences is also relevant in terms of what does and what does not constitute "disability." When I was eighteen months old, I was a burn victim. I was seriously burned and was in and out of the burns unit for a year and a half and then back for skin grafts over the next ten years. At the time, I did not identify as a disabled person. And yet I was regularly seeing doctors and I had to avoid activities which involved being out in the sun. I would always be encouraged to hide the burns on my arms and neck with long sleeve shirts. Somehow, as a child, having disfiguring burns, multiple operations, a lifestyle where I had to avoid the sun, and a social pressure to conceal my bodily imperfections did not seem the same as a disability. I was never offered any assistance or counselling to deal with my burns. No adaptations were made at school to make it easier for me to adjust (such as providing sun shades). I think that says a lot about both my own and society's perceptions of what constitutes a disability and how to respond to it. In retrospect, my burns probably did make me disabled from a very young age, before I even realised it.

Despite all the challenges I have experienced, I can see a lot of positive changes stemming from my invisible disabilities. They have stimulated a lot of soul searching within me. The accident made me change my approach to my family, to my work and to my friends. My values have become a lot clearer and I have a much clearer sense of what is important to me. One of the main changes I have noticed is in my relationships with others. I now have more understanding for other people's suffering and I feel very free to express my emotions. My life's philosophy has also changed and my priorities are different.

It may seem ironic to say that at the same time as I was experiencing the most profound suffering and distress of my life, I was also experiencing my greatest personal development. As a result of my accident, I am no longer competitive, I display my affection much more openly to people and I have learnt to deal with all the challenges that my disabilities have given me. Over time I became wiser, more considerate and in many ways a better person. I often find myself talking about the lessons learnt from my experience with other people going through tough times.

Nearly dying has taught me many lessons about how to live. It completely changed my character. I know I am more appreciative of pretty flowers, a lovely sunset, or a quiet day at home than I ever was before my accident. I also try to make the most of the time I have. My relationships with my wife, my friends and my family are so much more important than ever before. I laugh more often now. I am at peace with myself. Without my accident, these changes may not have happened.

I now realise that I will never be the same person again, that this traumatic experience has fundamentally changed me. I am a different person now, with different priorities, attitudes, beliefs and a completely different and diminished social network. I still grieve for

the "old me" sometimes, but hopefully the grieving will get less as time passes.

I have shared my story with you not because I want your pity. I do not. I would really like some of the barriers that prevent me from having a full and rich life broken down, attitudinal barriers like discrimination and negative attitudes towards disabilities. In this regard, I would really like to see invisible disabilities acknowledged as just as real as visible ones. I would also like to see the barriers disabled people experience in employment, the health system, accommodation, and many other areas broken down.

It has taken a lot of strength to deal with my accident. I have needed physical strength to deal with the large amounts of pain and emotional strength to cope with the challenges such as retraining my mind, getting to know myself again, coping with never-ending doctors appointments, and so on. It has been eight years now. I feel like I have done my fair share of adjusting. I only wish other people would do their share. People like the doctors who write you off, the landlords who balk at renting a house to you, the employers who will not give you a job because of your disability, the people who treat you as less valuable because of your disability, and so on...